

## WHAT IF MY BABY'S TEST IS ABNORMAL?

Your baby's doctor will be contacted if there are any abnormal or unusual test results, and will talk to you about the test results. An abnormal or unusual result does not always mean that a disorder is present. This is a screening test which finds those babies who may be at risk for a disorder. More tests are needed to find out if your baby really has a disorder. If you are asked to have your baby tested again, please do it as soon as possible.

There is also a chance that these rare disorders could be missed by this test since it is only a screening test.

## HOW ARE THESE DISORDERS TREATED?

Each disorder is different. Some disorders are treated with special diets and other disorders are treated with medications. If treated early, infants may grow up to lead a normal, healthy life. In a few cases, the disorders may not be completely treatable. The early diagnosis and treatment of the disorder will allow your baby the best chance of normal growth and development.

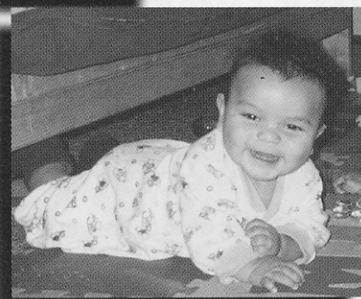
## DO YOU NEED MORE INFORMATION?

Call the Hawai'i Newborn Metabolic Screening Program at (808) 733-9069; TDD (808) 733-9055; or go to the following websites:

Hawai'i Newborn Metabolic Screening Program -  
<http://www.hawaiiogenetics.org>  
Oregon State Public Health Laboratories -  
<http://www.ohd.hr.state.or.us/nbs/index.cfm>  
Newborn Screen and Genetics Resource Center -  
<http://genes-r-us.uthscsa.edu>  
Save Babies Through Screening -  
<http://www.savebabies.org>

## THE NORTHWEST REGIONAL NEWBORN SCREENING PROGRAM IS A COLLABORATIVE PROJECT INVOLVING:

Oregon Department of Human Services  
Oregon Health & Science University  
Idaho Department of Health & Welfare  
Nevada State Health Division  
Alaska Department of Health  
and Social Services  
State of Hawai'i Department of Health



Oregon Department  
of Human Services

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In compliance with the Americans with Disabilities Act (ADA), if you need this information in an alternate format, please call Oregon State Public Health Laboratories at (503) 229-5882.

<http://www.ohd.hr.state.or.us/nbs/index.cfm>



## Testing Your Baby For Hidden Birth Defects



# Hawai'i

## The Northwest Regional Newborn Screening Program

## WHAT ARE "HIDDEN" BIRTH DEFECTS?

Hidden birth defects are problems in the body's ability to make and use hormones, proteins, sugars, blood cells, or to break down compounds such as proteins, fats, or carbohydrates into smaller substances needed by the body for energy, growth, and repair. Babies with these disorders look and act normal and seem perfectly healthy, even though they may be getting very sick. If identified early with newborn screening testing, some of these disorders can be treated before they cause serious health problems.

## WHAT IS THE NEWBORN SCREENING BLOOD TEST?

Your baby's heel is pricked and a few drops of blood are put on a special filter paper. This filter paper is allowed to dry and is then sent to the Oregon newborn screening testing laboratory. Your baby's blood is then tested for over 30 disorders which can cause serious health, developmental problems, and even death, if not treated early.

## WHO SHOULD HAVE A NEWBORN SCREENING BLOOD TEST?

State law requires that every newborn baby be tested. You may refuse to have your baby tested if it is against your religion. Parents, guardians, or other persons having custody or control of the child, who refuse the test, must sign a refusal form.

## IS THE BLOOD TEST SAFE FOR MY BABY?

Yes, the blood test is safe. Your baby will experience no additional physical discomfort beyond the heelstick normally done for newborn screening. The risk of infection is very low.

## WHEN SHOULD THE NEWBORN SCREENING BLOOD TEST BE DONE?

If your baby is born in a hospital, the newborn screening blood test should be done before your baby leaves the hospital, usually at one to two days of age. If your baby is tested before 24 hours of age, a second test should be done before your baby is two weeks old.

If your baby is born at home, your baby should be tested before seven days of age, preferably between one to three days of age.

## WHO WILL MAKE SURE THAT MY BABY HAS A NEWBORN SCREENING SAMPLE COLLECTED?

The doctor, nurse, or midwife who delivered or is caring for your baby should make sure that a blood sample is collected for testing. Ask your doctor or midwife about the newborn screening test results. The results should be available two to three weeks after your baby's birth.

## WHAT IF I MOVE?

Let your doctor know if you have a new address or phone number. This information is important if your baby needs further follow-up.

## HOW MUCH DOES THIS TEST COST?

The current cost of the newborn screening test is \$47.00. Most health insurance plans pay for the newborn screening test. If you do not have insurance or cannot afford the cost of the test, please call the Hawai'i Newborn Metabolic Screening Program at (808) 733-9069.

## WHAT DISORDERS ARE SCREENED FOR?

Newborns born in the state of Hawai'i are screened for the following disorders:

### ■ Endocrine (hormone) disorders:

- Congenital adrenal hyperplasia in which the adrenal glands are unable to produce normal amounts of certain hormones.
- Congenital hypothyroidism in which the thyroid gland cannot make enough thyroid hormone for normal body and brain growth.

### ■ Hemoglobin (blood) disorders:

- Sickle cell disease and other hemoglobinopathies in which abnormal hemoglobin in the red blood cells may cause anemia.

### ■ Metabolic (metabolism) defects:

- Biotinidase deficiency in which the body is unable to use biotin, a B-vitamin.
- Galactosemia in which the body cannot break down a sugar (galactose) found in milk.
- Amino acid (protein) disorders: a group of hereditary disorders caused by enzymatic defects, which result in the toxic accumulation of certain amino acids in the blood.
- Fatty acid oxidation disorders: a group of hereditary disorders caused by defects in enzymes which are involved in the breakdown of dietary and stored fats to energy.
- Organic acid disorders: a group of hereditary disorders caused by enzymatic defects which result in a toxic accumulation of certain organic acids in the blood.
- Urea cycle disorders: a group of hereditary disorders, caused by enzymatic defects which result in a toxic accumulation of ammonia in the blood.